

Genetic Services Section

Working with Communities

Work with four local health jurisdictions fosters prevention of secondary conditions for people with disabilities through grass roots community mobilization and partnerships between the public and private sectors within the community.

Living Room Forums provided an opportunity for residents to discuss issues related to newborn screening, equal access to genetic services, and genetic discrimination.

Genetic Service Utilization in Washington State

- Over 10,667 families received prenatal diagnosis and genetic counseling services at Washington's Regional Genetics Clinics in 2005.
- Pregnancy Risk Assessment and Monitoring System (PRAMS) data from 2003 indicate that 87.67% of pregnant women in Washington received counseling from their prenatal care provider regarding birth defects or genetic disorders.

The Genetic Services Section within the Office of Maternal and Child Health (OMCH) helps residents receive high quality genetic counseling, testing, evaluation, diagnosis, and treatment services. The Genetic Services Section is also responsible for evaluating genetic services, advising policymakers on genetic and disabilities issues, and making sure all infants born in Washington receive hearing screening and those with suspected hearing loss are referred for the services they need. The Genetic Services Section serves *all* Washington residents regardless of age, sex, or race/ethnicity.

Activities

- Coordinate and monitor statewide genetic services to over 10,667 families each year.
- Inform and educate families, health care providers, the public, and others about genetic issues.
- Monitor state and federal legislation on genetic privacy, confidentiality, and genetic discrimination as well as participating in forums where these issues are discussed.
- Ensure that newborns are screened for hearing loss and receive diagnostic and intervention services as necessary.
- Prevent secondary disabling conditions among people with disabilities and promote active lifestyles within their communities.
- Work with local communities to increase awareness of disability issues.

2005 – 07 Funding & Staffing

Funding for services comes from a variety of sources including the State General Fund, the Maternal and Child Health Block Grant (Title V) and other federal grants, and Title XIX (Medicaid).

Genetic Services employees include a program manager, six health services consultants, and a secretary.

For more information about the Genetic Services Section, please contact:

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Outcomes/Benefits

- Regional Genetics Clinics provide high quality genetic services to Washington residents so that families with, or at-risk of, genetic disorders can benefit from the latest technology and can make informed decisions about their own health and/or their reproductive choices.
- Practitioners and families receive information from trained genetic health care service providers that helps them identify options and develop health plans to prevent or lessen illness.
- Infants are screened for hearing loss prior to 1 month of age, receive diagnosis by 3 months of age, and begin intervention by 6 months of age through hospital-based universal newborn hearing screening programs and a statewide tracking and surveillance system.

Trends and Emerging Issues

- The growing identification of genes responsible for illnesses and the development of many new genetic tests are occurring faster than most health care practitioners' abilities to be knowledgeable about them and their potential benefits or limitations.
- Rapid advances in the field of genetics have outpaced efforts toward policy development and planning for an adequate workforce in the health care delivery system and public health arena creating the need for genetics education among multiple audiences.
- Genetic advances have resulted in a heightened concern for the privacy and confidentiality of genetic information as well as for the potential for genetic discrimination in the areas of employment and insurance.
- There is no formal mechanism in place for assessing the quality of clinical or laboratory genetic services.
- One in five Washington residents is affected with a disability yet little is known about how best to prevent secondary conditions such as bed sores, depression, or obesity.